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Background information, principles of service, and priorities for action preface a five year plan of operation to provide services for the cerebral palsied. Rationales, objectives, methods, timetables, financing, and programs are discussed for the following priorities: prevention and early care, comprehensive services for teenagers and adults; children with learning disabilities; information, referral, and followup services; architecture and technological aids; transportation; and service in rural and less populated areas. Priorities of implementation considered are staff training, development of a professional services program committee, and assistance to affiliates in planning and implementation which includes consultation and evaluation, influencing legislation, professional education, public information, demonstration projects, action research, and cooperative programing. A financing summary and a policy statement are presented. (RJ)

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THE IHF PLAN

The Individual with Cerebral Palsy and His Family

EC004011E

UNITED CEREBRAL PALSY ASSOCIATION, INC.
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NEW YORK, NEW YORK 10016
1969

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THE INDIVIDUAL WITH CEREBRAL PALSY AND HIS FAMILY 1969-1973

A. Background Information

1. Changes in the Delivery of Health Services

Continual evaluation of efforts to reach their objectives should be built into progressive organizations in all aspects of modern America. This is especially true for voluntary health agencies in relation to changes in delivery of services, the more rapid utilization of clinical research findings and the availability of more tax funds. Volunteers and staff must be aware of these developments and, indeed, help in directing them. The United States today is in the midst of a whirlwind of social, economic and cultural change. If we in United Cerebral Palsy are perceptive and skillful enough, these changes can be used to the advantage of children and adults with this disability.

As United Cerebral Palsy Associations approaches its 20th Anniversary, the staff of its naticnal Medical and Scientific Department felt it was urgent to work with its affiliates to evaluate current service programs and to make definitive plans for the next five years in relation to the development and delivery of appropriate services for handicapped children and adults.

2. Federal Government Programs

The tremendous thrust of Federal stimulation in support of research and service in mental retardation has been given added stimulus by recent broadening of the legislation to include individuals with physical disability. States are completing their vocational rehabilitation planning programs of the past two years and are starting to implement such programs

with matching Federal support. The Regional Medical Programs for heart, cancer and stroke are beginning to develop methods to bring quality medical care to disadvantaged citizens in these three areas.

The "Partnership for Health" legislation in the 1967 Congress culminated in the Comprehensive Health Care Planning Program, which is designed to improve the quality of health services rendered to citizens everywhere. All of these programs have significance for the future services of children and adults with cerebral palsy.

3. New Program of United Cerebral Palsy's Research and Educational Foundation

In June, 1967, the Foundation's Directors approved recommendations of its scientific advisors to gradually phase out its existing program in the basic biological, medical and behavioral sciences related to the normal and abnormal human brain. Its future efforts will concentrate on the stimulation and support of research studies related to suspected and known causative factors in brain dysfunction, such as (1) prematurity (children of low birth weight), (2) neurotropic virus and related infectious agents (German measles, salivary gland viruses, toxoplasmosis, etc.), (3) blood type incompatibility and (4) the clinical management of prenatal care, labor, delivery and resuscitation of the newborn.

4. Initial Phases of the United Cerebral Palsy Self-Study Method

With these developments of such potential importance to the delivery of health and special education services to individuals with cerebral palsy, it seemed appropriate to review the total United Cerebral Palsy organization of service programs. In September, 1967, the staff of the Medical and Scientific Department prepared a preliminary plan for the next five years for presentation to affiliates for their comments, additions and deletions.

The preliminary plan was distributed to affiliates in October with the request that each affiliate's Board of Directors, service program advisors and professional staff consider the material in depth and react to it in one of two ways: (1) Develop a critique in writing for submission to the national Medical and Scientific Department and/or (2) to send a representative to one of a series of six Regional Service Program Hearings (December 1967 - March 1968) to present the affiliate's views in person.

5. The Regional Service Program Hearings

Each hearing was organized similar to legislative hearings of government where one or more affiliate representatives "testified" before a peer panel consisting of a national officer, a regional vice president, a state president, representatives of national professional advisory committees (Services, Adult Activities, Special Education and Clinical) and an executive director of an affiliate. In addition to the "testimony" of each affiliate requesting to be heard, several special service presentations were made in the "Hearings." These were unique in content or methodology and deemed worthy of consideration for inclusion in the final plan.

Two special hearings were scheduled to include representatives of Federal government agencies and representatives of related voluntary health agencies to discuss their program efforts related to cerebral palsy, to recommend areas where such groups could work more closely with United Cerebral Palsy and areas wherein United Cerebral Palsy should take leadership in program development.

Each panel met after the hearings to review the material and develop appropriate recommendations to be considered by the Convocation, which consisted of a group of selected panel members from the six hearings and

which met in New York City in April, 1968. Convocation participants spent three days reviewing the mass of data and establishing priorities for implementation to be recommended to the United Cerebral Palsy Board of Directors through its Operating Board of Officers (meeting September 13, 1968) and Executive Committee (meeting September 14-15, 1968).

6. Potential for the Future

To our knowledge, this is the first time that a voluntary health agency has used this method to develop a forward-thinking master plan for service programming on a five-year basis. It has potential ramifications for all facets of United Cerebral Palsy's total program -- fund raising, public education, relationships to other agencies, community organization, etc. The useful and effective participation by well over half the United Cerebral Palsy affiliate family, by lay and professional volunteers on the panels, and by national professional staff has given a solid base to the recommendations for service program emphasis, the methods of United Cerebral Palsy's rendition and support thereof in the immediate future. A built-in aspect of this technique has been its insistence on periodic reevaluation of service efforts both by affiliates and the national organization.

B. Basic Principles of Services

The following are basic to all activities and provision for services by United Cerebral Palsy Associations to individuals with cerebral palsy:

(1) The person with cerebral palsy and his family are the main concern of this voluntary health agency.

(2) A lifetime partnership should be established from the time an affiliate and the family of a cerebral palsied individual come into contact. In effect, the affiliate would serve as a permanent resource for the cerebral palsied individual and his family. (See Section -- Information, Referral & Follow-along Services.)

(3) In addition to the person with cerebral palsy now served, it is appropriate that the concept of the disability with which the entire organization is concerned be broadened. UCPA on all levels should assist where possible children and adults with related disabilities.

(4) In order to provide an effective service to children and adults, it is necessary for UCPA to stress early identification of, and service appropriate for, all aspects of cerebral dysfunction. At the same time it must continue to see that community resources are adequate to meet the traditional, more readily recognized, medical, educational, vocational, social and recreational needs.

(5) A self-evaluation process should be a regular part of any service plan. "Program Hearings" or some similar procedure should be re-instituted as one component of these evaluative measures. With the assistance of National, Affiliates should also develop a procedure for a continuous reevaluation of their programs and methods of operation.

(6) Established priorities must be equally significant at all levels of UCPA organization. The local affiliate, in particular, should recognize that new programs are needed and must be initiated as present services are assumed by other public or private agencies or when additional funds become available. It should be a major objective of an affiliate to stimulate other public and private agencies to provide more services for individuals with cerebral palsy of the highest quality. Therefore, it is important that an affiliate demonstrate its willingness to be flexible in its approach and structure for program development. This will require an ongoing procedure for advance planning.

C. Priorities for Action -- 1969-1973

(See Diagram Page 12)

The "Aggregate Report of Affiliate Presentations" contains over 50 recommendations pertinent to expanding and improving service programs. These are a key resource for future planning. From these recommendations, the following items were given highest priority. These fall into two major categories: 1] Services to Individuals and Their Families; and 2] Methods of Implementation.

It must be emphasized that a well-trained staff on all levels of UCP operations was the single item most frequently recommended in all the Hearings and, therefore, was given highest priority by the Convocation. In the diagram on page 12 an effort is made to illustrate this by showing Staff Training as the undergirding for all of the service program priorities. It is also the link between the service aspects of the Plan and the methods of implementation.

I. SERVICES TO INDIVIDUALS AND THEIR FAMILIES

A. Primary Priorities

Two broad areas were identified as having primary and equal priority ratings:

1. Service Aspects of Prevention and Early Care

Clinical research has suggested methods for identifying high risk mothers and vulnerable infants, but these are not yet implemented on a nationwide basis. Therefore, high risk mothers are continuing to bring damaged infants into the world. A great many of these babies are not recognized early and, hence, do not receive the services which could prevent much future disability.

2. Services for Teenagers and Adults

Although some persons with cerebral palsy have benefited from vocational rehabilitation services, a majority do not have vocational potential because of severe and multiple disabilities or because of limited community resources. New patterns of service are needed for these individuals.

B. Secondary Priorities

The following additional services were identified as being of major importance but given a slightly lower priority rating.

1. Minimal Cerebral Dysfunction

Learning disabilities of organic origin affect many children with cerebral palsy. Other children with less obvious physical defects have the same kind of learning problems. Children with these problems should be served by UCP.

2. Information, Referral and Follow-Along Services

The needs of children and adults with cerebral palsy change at various stages in growth and development. UCP should serve in the role of a lifetime partner to these individuals and their families in helping them to obtain and utilize the right service at the right time.

3. Nationwide Approaches To:

a] Architecture in Relation to Service Programming

UCP has a responsibility which goes beyond elimination of architectural barriers in public buildings. Multihandicapped children and adults frequently are excluded from existing services because of architectural barriers, inadequate space arrangement or layout or unsuitable equipment. UCP should have a concern that facilities are designed which will make it

possible to program effectively for individuals regardless of the extent or severity of their disabilities.

b] Transportation

Programs for individuals with cerebral palsy frequently are under utilized because those who need the services cannot get to them. Planning of transportation of client to the services and vice versa should be an integral part of all program development. Various alternatives have been tested. Comprehensive studies are urgently needed to determine the most effective methods in relation to cost and to local situations.

c] Services in Rural Areas

Almost inevitably, facilities and services are concentrated in urban areas. Some approaches have been used to bring services to those living in less populated locations. These must be evaluated and new ideas for cerebral palsy services need to be evolved and implemented.

II. PRIORITIES OF IMPLEMENTATION

A. Staff Training Related to Services

As noted above, this received the highest priority and permeates all facets of service program planning as well as of implementation.

B. Professional Service Program Committees

Effective planning and implementation of program expansion and improvement depend to a large extent upon a viable and knowledgeable Professional Service Program Committee, a Standing Committee of the Board of Directors, which should include both professional and lay members. It should be an action group as well as an advisory group. At the national

level this Committee will function by means of Task Forces structured to deal with specific program areas on an ad hoc basis.

C. Assistance to the Affiliates in Service Program Planning and Implementation

1. Consultation and Evaluation

Affiliates should have available to them consistent and knowledgeable guidance on all aspects of service programs and assistance in periodic evaluation of their activities. Standards should be established for the operation of various facets of program; and ultimately these will lead to a process for accreditation of services and facilities.

2. Legislation In Service Programming

Local, state and federal governmental agencies are providing or paying for more and varied services to handicapped people than ever before in our history. UCP affiliates need guidance and assistance in taking advantage of these programs; or in stimulating legislation for new aspects of program.

3. Professional Education

The professional community as a whole needs and can take advantage of opportunities to increase its knowledge and skills in assisting individuals with brain dysfunction. UCP has pioneered such professional education but has limited it to a relatively few professions. A broader and more intensive effort should be made to reach all the specialties involved.

4. Public Information and Education

An intensive public education program is needed to dramatize and delineate the service aspects of UCP's activities. The goals should be: to assist in prevention; the need for earlier recognition and a broad

approach to treatment; plus greater public understanding and acceptance of the individual with cerebral palsy so that he may take full advantage of whatever his community has to offer.

5. Demonstration Projects

In order for many affiliates to institute new and well-designed programs of service in their areas, or for completely new ideas to be tested out, there is a need for "seed money" to demonstrate the validity of such approaches. National UCPA should allocate funds for pilot or demonstration service programming to assist affiliates. These "seed monies" can frequently be used to obtain matching funds from related private and public agencies.

6. Action Research

The need for clinical research should be brought to the attention of UCPA's Research and Educational Foundation as well as to other resources for research support. Knowledge that has been accumulated through basic research becomes sterile unless applied to the prevention or amelioration of the problems of the disabled.

In its new program UCP's Research Foundation should consider the stimulation and funding of clinical research programs relating to prevention in order to expedite clinical application of basic research findings.

7. Cooperative Programming

At local, state and national levels the potentials for planning and implementation of services in active cooperation with other agencies have not been fully exploited. While protecting the interest of children and adults with cerebral dysfunction, UCP can exert leadership in many aspects of cooperative programming to strengthen and extent community services.

THE INDIVIDUAL WITH CEREBRAL PALSY AND HIS FAMILY

"A LIFETIME PARTNERSHIP WITH UCPA"

PREVENTION AND EARLY CARE

PROGRAMS FOR TEENAGE AND ADULTS

RELATED CEREBRAL DYSFUNCTION

INFORMATION REFERRAL AND Follow-ALONG SERVICES

NATIONWIDE APPROACHES TO
1. ARCHITECTURE FOR PROGRAM
2. TRANSPORTATION
3. RURAL AREA SERVICES

UCPA STAFF TRAINING AT ALL AGENCY LEVELS

PROFESSIONAL SERVICE PROGRAM COMMITTEE
TASK FORCES ------- REGIONAL COUNCIL

ASSISTANCE TO AFFILIATES IN PROGRAM PLANNING & IMPLEMENTATION

CONSULTATION & EVALUATION
LEGISLATION IN SERVICE PROGRAMMING
PROFESIONAL EDUCATION
PUBLIC INFORMATION & EDUCATION

DEMONSTRATION PROJECTS
ACTION RESEARCH
COOPERATIVE PROGRAMMING

I. SERVICES TO INDIVIDUALS AND THEIR FAMILIES

A. Primary Priorities

1. Prevention and Early Care

a. Rationale

The United States lags far behind many other nations in reducing infant mortality. Health statistics show great gaps in reaching pregnant women who need help to deliver healthy infants and in reaching babies who do not develop within normal range but may or may not look abnormal at birth. These are called "high risk" mothers and "suspect" or "vulnerable" infants.

Clinical research has developed methods of identifying high risk mothers and babies. Other nations have put these new findings to work and significantly lowered their rates of infant damage and mortality. With the help of Children's Bureau grants, a few communities have begun to develop high risk registers and started programs of more intensive care for high risk mothers. (One local UCP affiliate already has cooperated effectively in a "Maternal and Infant Care Project" of this type.) However, none of these projects are yet fully implemented and there is no unified nationwide program to detect the potential high risk infant early. There is great need for comprehensive follow-up and service programming for the high risk infants involved (including those identified in the Maternal and Infant Care Project areas).

There are over 18,000 children with cerebral palsy and over 126,000 with mental retardation born each year in this country. A great many of these babies receive little or no care during

infancy. Even when medical follow-up is provided, there is lack of due attention to early signals of potential learning disability (which may or may not be due to mental deficiency). As a consequence, at school age these children may be more handicapped than they needed to be even at this early age. They may be rejected from regular classes, inappropriately placed in special classes (often poorly equipped to treat their learning disorders of neurological origin), or pointed towards institutional care.

Research has suggested ways to ameliorate and circumvent "secondary retardation" or superimposed emotional disorders by earlier identification of sensory-motor or environmental barriers to growth and development. New services could be brought to bear during infancy to enhance the learning and other potentials of the child and to help families understand and better cope with their handicapped child.

In summary service programs must be developed to implement what is now known from research in primary and secondary prevention.

b. Methods

1) Highest Priority has been designated for UCPA to undertake a spearhead role in these service programs of prevention and early care. Such UCP service programs deserve due consideration for possible cooperative support by the UCP Research and Educational Foundation through its Task Force mechanism.

It is hoped that other voluntary health agencies interested in chronic neurological disorders of childhood, such as for those who are retarded, have epilepsy, or with learning disorders,

and the related governmental agencies who share such common interests will join with UCPA in these new and more vigorous approaches to prevention and earlier comprehensive services for infants.

The combination of a Task Force with staff effort, as suggested in Phase I, should provide a body of knowledgeable and effective workers from many disciplines. The selected demonstrations of Phases II and III should be a guide to continuing effort on the part of United Cerebral Palsy and an important opportunity for collaborative action supported by related public and private agencies.

2) Specific Project Outline

a) Phase I - Establish a "TASK FORCE" on Prevention and Early Care (as an ad hoc committee of the Professional Services Committee)

(1) Membership -- highly knowledgeable people in these fields:

-- to include representation from state and local UCPA affiliates; UCPA's Research and Educational Foundation; Children's Bureau, Social and Rehabilitation Service; national private agencies concerned with retardation, epilepsy, learning disorders of neurological origin, etc. with appropriate staff.

(2) Purpose of the Task Force: to accomplish the objectives as set forth below, to develop practical methods for cooperative demonstrations with official agency programs in maternal and child health, those geared to the high risk mothers in socially and culturally deprived groups, and related private agency programs.

(3) Objectives of this Task Force are:

At the national level

-- To accumulate and review comprehensively the scientific and public education literature in these fields. The preparation of position papers with bibliography for guidance of the Task Force and for dissemination to UCPA personnel and programs at all levels is an important corollary.

-- To plan for a national conference on "PREVENTION AND EARLY CARE" to include Task Force members and specialists in specific phases of the problem to recommend areas of most pressing need and ways by which UCP can exert appropriate leadership.

-- To stimulate appropriate applications for funds for demonstration programs which meet the program's objectives.

At the state level

-- Form a Task Force on Prevention and Early Care in cooperation with organized medicine. [If the state Professional Services Program Committee has been activated, the Task Force should be one of its ad hoc subcommittees. If the state has not yet or is in the process of formulating its Professional Services Program Committee, this Task Force could be a nucleus from which representatives are chosen to serve on the larger committee as it evolves.]

-- Objectives of the Task Force: -- to identify where maternal and infant projects have been started in the state; determine the present level of operations; determine the unmet needs; and stimulate the activation of an infant follow-up program where none exists.
-- To urge and cooperate in the formation and utilization of a registry of high-risk infants and related maternal and infant care projects.
-- To determine public and private agency interests and efforts in this field, their current level of operations, plans for the future, their evaluation of unmet needs and possibilities for cooperative action and support.
-- In cooperation with local affiliates to determine what local or county programs of early detection and more effective prenatal care and to offer active UCP cooperation.
-- Ascertain possibilities for demonstration projects. [See Phase II and sponsor collaborative state supported demonstrations of UCP concern and action, in close liaison with the national UCPA developments along these lines.]

<u>At the local level</u>

-- To identify <u>high risk mothers</u> and <u>high risk newborns or infants</u>. The establishment and utilization of appropriate local registries are key factors in the accomplishment of this objective.

-- To establish or strengthen local professional services available to determine early deviations from normal in high risk mothers and high risk infants.

-- To concomitantly establish other measures to remediate the condition of high risk mothers in order to improve their general health prior to delivery and/or future pregnancy.

-- To provide a program for more complete evaluation to suspect infants and to establish an appropriate program of management for such children.

-- To provide recurrent evaluation and continuing management as the previously high risk infant increases in age.

b) Phase II - Demonstration Programs

(1) Allocate funds to Task Force as seed monies to facilitate grants for project demonstrations.

(2) Support of actual demonstrations of optimum programs; provide for allied professional education; make consultants available for community programming, etc.

Sites and projects selected to be those where demonstrations can be made to show how the voluntary agency can augment a community program to make it effective. For example, a maternal and infant project and/or a university based project can be coupled with the effort of a UCP affiliate (and hopefully a cooperative effort with other local health agencies) to increase quality and quantity of care for high risk

mothers and suspect infants.

(3) Task Force Activities: to maintain close contact with these demonstrations; to disseminate information coming from these projects, for use by UCP affiliates and others.

c) Phase III - Study and Publication of Project Data Timetable

Phase I -- 1969

Phase II -- 1970-71

Phase III -- 1972-73

d) Financing

Fiscal 1968-69

Two meetings of Task Force	- $4,000
Development of Materials (Literature, Audiovisual, etc.)	- 3,000
Professional Services	- 4,000
	$11,000

Fiscal 1969-70

Two meetings	-$ 4,000
Materials	- 5,000
Honoraria and Travel	- 2,000
Professional Services	- 2,000
	$13,000

NOTE: Seed money for demonstrations are provided for in Section II-C-5

Fiscal 1970-71]
] Approximately the same as
Fiscal 1971-72] for 1969-70.
]
Fiscal 1972-73]

2. Comprehensive Services for Teenagers and Adults

a. Rationale

The teenager or adult with cerebral palsy has many problems and needs, but is most often neglected in terms of consistent services. This is especially true of handicapped teenagers and adults who cannot be employed in competitive or sheltered vocational environments. These individuals are "the disemployed" and affiliates are increasingly recognizing the needs of these individuals in their areas. However, the problem is the mobilization of resources and the utilization of methods to develop and sustain activities for this group in order to give dignity and purpose to their lives.

b. Objectives

1] Promotion of an effective continuum of services with special attention to those individuals who are excluded from existing services: providing guidance and follow-along counseling for client and parents as early as possible; continuing medical, psychological, social and vocational review toward realistic life goals. Those usually excluded from services are:

-- The severely handicapped person with limited potential.

-- Those individuals not likely to make a vocational adjustment through existing educational and vocational services.

2] Establishment of life enrichment programs with suitable recreation for all ages, focused toward learning to live with as great a degree of independence as possible.

3] Provision of vocational habilitation services with more adequate vocational training and/or sheltered employment, including work activity centers and new approaches to vocational programs. These should be augmented by the two first objectives and not conducted in isolation from related services.

b. Methods

1] Organize and conduct a national conference whose purpose would be:

-- To bring together individuals having theoretical and practical knowledge of the needs of non-working teenagers and adults in our society, who are socially and culturally deprived because of multiple handicaps and present-day attitudes toward acceptance of disability.

-- Ascertain the scope of the problem -- including an attempt to identify why such severely handicapped people are socially and culturally deprived; determination of what has been done to meet the problem in a variety of areas; and to project directions for immediate and long-range action.

-- Develop guidelines for utilization of a variety of methods, materials and media which can be used by community agencies in helping such persons to become participants in and to feel accepted by society.

Planning for this conference was started in April, 1968.

2] Establish a Task Force on teenage and adult comprehensive services:

-- Membership will include knowledgeable persons from public and private agencies, and from the "consumer" population with appropriate staff.

-- Objectives:

-- To foster and implement the findings and recommendations of the national conference into active community programs.

-- To develop a master plan for a comprehensive and coordinated attack on the problem.

-- To design and stimulate the activation of demonstration or pilot projects.

-- To develop a "how-to" manual for affiliates and professional workers in the field.

-- To design a program unit which would include all necessary materials such as curriculum and program development guides for the affiliates.

c. Timetable

1968 -- Hold the Conference.

1969 -- Organize Task Force to implement Conference recommendations.

1970 -- Continue work of Task Force, including publication of some materials.

1971 -- Publication of additional materials. Hold two Workshops. Provide Consultants.

1972 -- Hold two Workshops.

Provide Consultants.

1973 -- Same as 1972.

d. Financing

Fiscal 1968-69	-- Conference (UCPA's Share)	-	$ 1,500
	[Grant request for approximately $10,000 has already received preliminary approval by SRS Research and Training Division]		
	Meeting of Task Forces	-	1,500
	Professional Services	-	1,500
	Materials	-	2,500
			$ 7,000
Fiscal 1969-70	-- Meeting of Task Force	-	$ 1,500
	Professional Services	-	2,000
	Materials	-	2,500
			$ 6,000
Fiscal 1970-71	-- Materials	-	$ 2,500
	-- One Workshop	-	4,000
	-- Professional Services	-	2,000
			$ 8,500
Fiscal 1971-72	-- Two Workshops	-	$ 8,000
	-- Materials	-	2,500
	-- Professional Services	-	3,000
			$13,500
Fiscal 1972-73	-- Same as 1971-72	-	$13,500

B. Secondary Priorities

1. Related Cerebral Dysfunction

a. Rationale

Studies made since the founding of United Cerebral Palsy Associations have shown that certain types of learning problems may occur in children with brain dysfunction which impede school progress. While authorities differ as to the cause of these problems, most agree that organic brain dysfunction is involved. There are rather well-defined characteristics by which these special types of learning disabilities are recognized. Problems of perception, difficulties in abstract conceptualization, short attention span, and rapid mood swings are among the factors which interfere with the learning process. In addition, a child of this type who hears well may still have problems in pitch discrimination to the extent that a sharp command in a potentially hazardous situation may convey no greater sense of urgency than a quiet request to pick up a toy. Obviously, such difficulties can affect many interpersonal and emotional relationships as well as scholastic achievement of these children.

As some United Cerebral Palsy diagnostic teams became increasingly skilled in detecting these types of learning disorders, many new patients with learning problems who did not obviously have cerebral palsy were referred for evaluation. Physicians found that some of these youngsters were unusually awkward or clumsy and poorly coordinated. These children were admitted into affiliate school programs where teachers were

becoming increasingly sophisticated in helping to circumvent the special learning problems.

It is becoming increasingly apparent that these special learning problems affect other children who do not appear to have neuromuscular involvement. Different "labels" are attached to these youngsters, such as "Minimal Neurological Handicap", "Organic Learning Disorders", and "Brain Damage Syndrome".

Many scientists now point out that there are children with overt cerebral palsy, others with sub-clinical types of neuromotor involvement, and still others with no neuromotor problem who have, in common, special learning disorders which appear to be due to organic brain dysfunction.

Affiliate representatives at the service program "Hearings" and at the "convocation" stated that no child with related handicaps should be excluded from a UCP facility when his learning problems can be diagnosed and remediated in an affiliate program. UCP affiliates should urge the formation of public school classes to manage children with these special learning problems. Children with cerebral palsy who need this particular educational approach should not be arbitrarily excluded from these classes because they cannot walk or have other physical impairments.

There is also increasing evidence of considerable overlap within the factors which cause cerebral palsy, sub-clinical neurological manifestations of the disorder, and the more related neurological handicaps characterized by the clinical signs noted

above. Therefore, the focus on research related to causative factors adopted by UCP's Research and Educational Foundation will be concerned with preventing related brain dysfunction as well as moderate and severe degrees of physical involvement.

b. Methods

1] Recommended Policy Statement

It is recommended that the United Cerebral Palsy Associations affirm its concern with the child with related brain dysfunction and where possible extend its service programs to these individuals on all levels of the organization's activities.

2] Organization of a Task Force with these Objectives:

-- Comprehensive evaluations to detect perceptual and related learning problems of organic origin early in life.

-- Service programs to incorporate findings now available from research to remediate or alleviate these learning disorders.

-- Recognition that learning begins **during** early infancy and due concern must be directed to the needs of the child under 18 months of age as well as older children.

-- Incorporation of present knowledge about these children in the training of students in medicine, nursing, therapy, early childhood education and the other professions involved in earlier recognition and treatment and in helping families to

more adequately cope with their needs.

-- Helping the community Boards of Education design school programs for children with these types of learning disorders and being sure that those who share similar learning disabilities will not be excluded from service because they may also have physical handicaps.

-- Through clinical research, demonstrate the value of new evaluation and training methods.

-- Demonstrate these new approaches to community services in cooperation with other interested private and public agencies by the skillful use of seed monies.

-- Appropriate service program policies and priorities made by Affiliate Boards of Directors, should reflect UCP's broad service and special education programs for children with related brain dysfunction in addition to its program interests for the child with physical defects.

It is especially recommended that the United Cerebral Palsy affiliate share with related community agencies interested in the child with related brain dysfunction its joint concerns and interests, find all appropriate measures to cooperate effectively in attaining mutual goals, and invite the agencies to join with United Cerebral Palsy Associations in cooperative programming for these children.

c. Timetable

Basically, the changes needed to implement this priority will come as the result of intraorganizational education, plus the use of demonstration programs. A beginning should be made during 1968-69 by constituting a Task Force to determine the steps necessary to accomplish this at various levels of the organization, and to start with the development of guidelines for so doing. Completion of the guidelines and publication of same should be feasible during 1969-70.

d. Financing

Fiscal 1968-69	--	Professional Services	- $2,000
		One Meeting of Task Force	- 1,500
			$3,500
Fiscal 1969-70	--	One Meeting of Task Force	- $ 1,500
		Professional Services	- 2,000
		Publication	- 3,500
			$7,000
Future years	--	To be absorbed by usual intraorganizational program without additional funds.	

2. Information, Referral and Follow-Along Services

a. Rationale

The personal and family problems caused by cerebral palsy are most complex. The variety of needed services requires ongoing assistance to the family from a knowledgeable and continuing source. In effect, the UCP affiliate establishes a lifetime partnership with the cerebral palsied child and his family through an Information, Referral and Follow-Along Service.

This Service also informs an affiliate about existing gaps in services and serves as a base for overall planning for the future.

b. Methods

1] Role of local affiliates:

-- Establish an Information, Referral and Follow-Along Service available to all those with cerebral dysfunction and their families including also mothers-at-risk, suspect infants and their parents.

-- Give specific assistance in locating the proper resources needed by the family and providing the necessary assistance in making the best use of that resource.

-- Make a periodic check on inactive cases, at least every six months, to see if services are needed.

-- Data gathering pertaining to mothers-at-risk, high risk infants, and children with developmental deviations should be geared to eventual computer collection and analysis on a local, state, regional and national basis.

2] Role of national:

-- To provide stimulation and guidance through the distribution of materials, consultative services and organization of pertinent program discussions at regional workshops.

-- National should procure consultation and guidance on methods of data gathering so that, if indicated, a computerized system can be devised for local, state, regional, and national analysis.

c. Timetable

Beginning in 1968 -- Assistance to affiliates through consultation, appropriate program workshops and distribution of relevant materials.

1969, 1970 -- Find consultative resources to help develop a data gathering (tracking) system, which may lead toward computer collection and analysis, where indicated.

1971 -- Hold national workshop for those affiliates which have established an Information, Referral and Follow-Along Service; or those that wish to do so and are willing to computerize a computerized system.

d. Financing

Fiscal 1968-69	-- Materials	- $1,000
Fiscal 1969-70	-- Professional Services to develop tracking system	- $3,000
Fiscal 1970-71	-- Professional Services	- $3,000
Fiscal 1971-72	-- Professional Services	- $1,500
	Workshop (East)	- 5,000
		$6,500
Fiscal 1972-73	-- Professional Services	- $1,500
	Workshop (West)	- 5,000
		$6,500

3. National approaches to:

a. Architecture and Technological Aids Related to Programming

1] Objectives

-- To involve the field of architecture and engineering sciences in the development and promulgation of services to children and adults with cerebral palsy, many of whom are currently excluded from programs because they have severe and multiple disabilities.

-- To influence architects and engineers on the special needs and requirements of people with multiple handicaps in public and private buildings and in specialized facilities. To interest architectural firms in these problems and to influence them to consult UCP and related agencies when designs of facilities for use by handicapped people are being developed.

-- To influence curricula in schools of architecture and engineering sciences in the special habilitation problems of multi-handicapped people: barriers, arrangement and adequacy of space, use of color, lighting, natural environment as adjuncts in providing more effective facilities, modification of existing ones and proper equipment.

2] Methods

-- Development of a close liaison with the American Institute of Architects and related private and public groups and through them to their state chapters.

-- Evolvement of a list of architectural and engineering firms interested in the problems of handicapped people and a group of UCP consultants in architecture.

Provision of consultative services to affiliates related to structure-for-function.

-- Development of guides, manuals, sample blueprints and drawings with publication in architectural journals and UCP publications.

-- Use of Environment Research Center and active cooperation with architectural barriers programs of other organizations.

-- Interesting schools of architecture to modify their curricula to include appropriate materials for architectural students on service programming.

-- Appointment of a Task Force of architects, engineering scientists and service program planners to assist National UCP and its affilitates in developing realistic policies and programs wherein architecture plays a key role.

-- Review of National Building Fund Exemption Policy and National's recommendation of not investing UCP funds in buildings.

-- Provision of consultative service to states in the construction and modification of existing residential facilities.

3] Timetable

Fiscal 1968-69	Initial conference and Task Force Meeting
Fiscal 1969-70	Publication of materials
Beginning 1969	Development of working relationships with other organizations.

4] Financing

Fiscal 1968-69	-- National Conference		
	-- 30 people	-	$7,500
	-- Task Force Meeting	-	1,500
	-- Professional Services	-	2,000
			$11,000
Fiscal 1969-70	-- Task Force Meeting	-	$1,500
	-- Professional Services	-	2,000
	-- Materials	-	5,000
			$8,500
Future Years	-- Professional Services	-	$2,000

NOTE: It may be possible to secure special contributions toward this program from one or more architectural or engineering firms.

b. Transportation

1] Rationale

The cerebral palsied child or adult must be provided efficient, comfortable and safe transportation to and from places outside the home where various types of service are available for him -- clinics, treatment centers, school, recreation, socialization programs, work activity, vocational habilitation, etc. and to appropriate community agencies and houses of worship. Community transportation should be provided through UCP stimulus. Transportation is also needed to bring special services to the cerebral palsied client in his home or place of residence especially in sparsely populated areas.

2] Methods

National:

-- Compilation of UCP affiliate and related agency experiences in providing transportation with appointment of a Task Force to study UCP's transportation problems and evolve practical solutions.

-- Development of an effective working relationship with U. S. Department of Transportation and various experts in the provision of bus, automobile and other vehicular services to ascertain organizational problems in provision of such services and to work toward their solution. To educate the purveyors of services in adapting equipment to the special needs of handicapped persons.

-- Determination of cost factors and ways and means by which transportation expenses can be provided.

-- Planning and execution of a national conference of experts in all phases of transportation with possible followup by regional and/or state conferences.

-- Provision of a manual for UCP affiliates on methods, costs and solution of special transportation problems, including volunteer corps, commercial transportation, liability insurance, training programs, etc.

-- Utilization of Transportation Task Force members as part-time national consultants throughout country.

Affiliate

-- Organization of transportation committee to utilize National guidelines and adapt them to local situations.

-- Organization of a volunteer transportation corps with regular scheduling, coordination, cost analysis, follow-up, vehicle procurement.

3] Timetable

1969 -- Appointment of Task Force and one meeting of same.

1970 -- National Conference and Publication of Proceedings.

1971 -- Regional and/or State Conferences.
Use of Transportation Consultants.

1972 -- Follow-up survey and publication of collective experiences.

4] Financing

Fiscal 1968-69	--	Professional Services	- $2,000
	--	Task Force - One Meeting	- 1,500
			$3,500
Fiscal 1969-70	--	National Conference	- $11,000
	--	Professional Services	- 2,000
	--	Task Force Meeting	- 1,500
			$13,500
Fiscal 1970-71	--	Materials	- $3,000
	--	Professional Services	2,000
			$5,000

NOTE: Role of national organization will be reevaluated in 1970-71.

Possible Funding Alternatives

-- Application to SRS for grant to support conference and proceedings.

-- Support by U. S. Department of Transportation, labor unions, related agencies.

c. Service in Rural and Less-Populated Areas

1] Rationale

Despite the urbanization of America today, there exist vast reaches where people with handicaps live who cannot be active in community service programs. UCP has an important role to assist such clients by providing services in the home, village or nearby facility, to bring the client to useful services where they exist and to train family and related team members in such rural communities.

2] Methods

-- Determine the need for development of services for individuals in less well populated areas by use of a Task Force.

-- Activate recommendations for home care, for clinical and/or demonstration research and transportation to the nearest programs when essential.

-- Train family members, itinerant therapists, social workers or nurses in the management of such clients on an interim basis.

-- Develop regional workshops on new methods of providing services to handicapped people in rural areas.

-- Recommend the extension of the Elks' home service programs, its activity using transient therapists, etc.

-- Study the role of educational television in work and social activity (i.e., utilization of Australian "outback service").

-- Develop interest in the problem through the Grange, home demonstration agents, public health nurses, etc., and utilize such groups in providing necessary services.

-- Establish liaison with comprehensive health planning and regional medical programming in rural areas.

3] Timetable

1969 -- Staff Planning.

1970 -- Establishment of a Task Force and one meeting of same.

1971 -- Develop guidelines and publications.

1972] -- Continue 1971 activities.
1973]

4] Financing

Fiscal 1968-69	-- Staff Planning - no expense	- ------
Fiscal 1969-70	-- One Meeting of Task Force	- $1,500
Fiscal 1970-71	-- Meeting of Task Force	- $1,000
	-- One Regional Workshop	- 4,000
	-- Professional Services	- 2,000
	-- Materials	- 3,000
		$10,000
Fiscal 1971-72	-- One Regional Workshop	$ 4,000
	-- Professional Services	2,000
		$ 6,000
Fiscal 1972-73	-- Professional Services	$ 2,000

NOTE: There are rural service implications in all other service activities, such as Prevention and Early Identification.

II. PRIORITIES OF IMPLEMENTATION

A. Staff Training Related To Services

1. Rationale

Staff training is essential to competent delivery of services for cerebral palsied people at all organizational levels. Urgent recommendations for upgrading such training came from affiliates in all sections of the country and it was given top priority at the Convocation.

Objectives

-- To impart information that is required to implement the tasks necessary to achieve the purpose for which UCPA exists; to effect more rapid application of research findings; to upgrade service program staffs at all levels in order to provide quality service; to train staff at all levels in new areas to ensure comprehensive services becoming a reality and not continue programs merely because of familiarity or for comfort of the staff and Board.

2. Methods

a. National Leadership in Goals

A key function of national service agencies is to disseminate accurate and up-to-date information concerning service program philosophy, needs, objectives and methods of rendering service. This should be tailored to the training needs of care and administrative staff; and communicated via effective methods.

b. Designated Responsibility

-- Assign national staff to educational responsibilities.

-- Establish a Staff Training Task Force with representation from the Professional Services Program Committee and from such professional associations as the National President of UCPA may deem advisable to act as Advisory Council to the National office.

-- In addition to in-staff training at any level, the national office, in consultation with the Staff Training Task Force, should recommend continuing education courses developed by other agencies such as National Health Council, Association of Rehabilitation Centers, and related professional associations; and assist in securing financial support for the conduct of such projects where possible.

c. Methods for Staff Training

-- Compilation, dissemination and interpretation of pertinent existing material from UCPA or other agencies, such as news bulletins to affiliates concerning practical program pointers.

-- Development of instructional guides containing various types of service programming methods for the person with cerebral palsy and his family.

-- Conduct or sponsor seminars or workshops for dissemination of new materials and development of new staff skills.

-- Regularly scheduled orientation programs for new staff personnel on all levels (field representatives, state executives, etc.) should be the responsibility of the national organization.

-- Inservice training for staff personnel on problem areas related to:

-- organization of service programs, administrative procedures, budgeting and reporting, fiscal management, personnel management.

-- direct operation of services -- with emphasis on appropriate priorities.

-- training should focus upon developing and upgrading program skills of staff and should be regularly scheduled.

-- Service program information for staff training is included in the recommendations for UCP's future program emphasis.

3. Timetable

1969 -- Assignment of the Staff Members to the related training areas.

-- Establishment of the Task Force.

-- Start development of materials.

1970 -- Publication of materials, visual aids, etc.

-- Training workshops.

1971]
1972] Continue activities initiated in 1969-70.
1973]

4. Financing

Fiscal 1968-69 -- Meeting of Task Force	-	$1,500
Inservice Training Session	-	5,000
		$6,500
Fiscal 1969-70 -- Meeting of Task Force	-	$1,500
Inservice Training Session	-	5,000
Materials	-	3,500
		$10,000

Fiscal 1970-71]
]
Fiscal 1971-72] -- Same as for 1969-70.
]
Fiscal 1972-73]

B. Professional Services Program Committee

1. Rationale

National UCPA's Professional Advisory Committees have performed a valuable function by enlisting representatives of a broad spectrum of disciplines. At times, however, they have found that their responsibilities overlap; and that the sum total of recommended actions exceeded available staff and financial resources.

In local and state affiliates, a satisfactory merging of the professional advisory and program action roles is urgently needed as UCP moves into the next decade.

2. Methods

It is urgently recommended that National UCPA structure a standing committee of the Board to be designated as the Professional Services Program Committee. This Committee should include representatives, on a rotating basis, of all the disciplines related to cerebral palsy services. Affiliate participation should be provided for by a Council of Regional Representatives which would be advisory to the Committee and serve as one avenue of communications between the affiliates and the Committee. The Committee would perform its functions through action-oriented Task Forces which would be constituted as ad hoc committees to deal with specific areas of activity.

It is recommended that most local and state affiliates will form similar committees which can relate more closely to the national structure.

3. Timetable

Since this committee reorganization will involve changes in the By-Laws, it cannot be made effective until after the 1969 Conference. It is proposed that during the interim period the Task Forces will

function as outlined in other sections of this report.

4. Financing

The basic funding of Committee and Task Force meetings, as well as for staff time, will be budget items annually for UCPA, Inc. Many of the projects which will be developed by the Committee and Task Forces can be funded in large part by grants from government, or other voluntary agencies if there are matching monies available. An application has already been submitted to the Social and Rehabilitation Service of Health, Education and Welfare for approximately $10,000 (to be matched by $1,500 of UCPA funds) for the purpose of a conference to delineate the methods for developing appropriate services for non-working teenagers and adults. This has received preliminary approval. In Fiscal 1968-1969 preliminary budget estimates for the functioning of Task Forces are incorporated into the several proposals contained in the report. Therefore, the only budget request for the coming fiscal year is for one meeting of the Professional Services Program Committee which would be held subsequent to the 1969 Conference.

Fiscal 1968-69 -- One Meeting - $2,500

For each of the ensuing four years, it is anticipated that two meetings of the Committee will be required annually, plus two meetings of the Council of Regional Representatives.

Fiscal 1969-70 and ensuing years -- Committee meetings [two each year] - $5,000

-- Council meetings [two each year] - 3,000

$8,000 each year

C. Assistance to Affiliates in Planning and Implementation

1. Consultation and Evaluation

a. Rationale

All agencies subsisting on public funds, whether from voluntary or tax sources, must adopt all possible measures to insure that monies are used to provide or purchase services of the highest possible caliber. When funds are limited it is even more essential that they be used to meet the most pressing needs. Volunteers who lend their names, time and energy to a cause have the right to expect that the services and personnel of the agency meet minimum standards of performance.

Increasingly, various third parties, such as governmental agencies and insurance companies, are providing grants for, or purchasing services from, voluntary health agencies and with such support increasing pressure for adoption of standards and ultimately for accreditation of service programs.

b. Methods

Role of National

National UCPA should provide guidelines as a step toward development of standards for quality service programs. UCPA has three major roles:

(1) To assist affiliates utilizing team studies and self-evaluation techniques.

-- UCPA needs a stronger policy relating to affiliate service program studies, including a method for periodic followup of recommendations made.

-- Built into this process is the recognized obligation to take specific action on the recommendations made.
-- There should be a regular review of results of implementation of such service program studies.
-- Any evaluation should include recommendations for a review of the Board structure and function. It may be necessary to develop regional teams to work with Boards and staff to better educate and inform them on total services for the cerebral palsied and directions that the affiliate may take within its competency, resources and potential for change.

(2) Hearings on a regional basis should be held every few years to serve as a catalyst for program self-evaluation at all levels.

(3) In cooperation with professional groups standards should be set for the delivery of services to cerebral palsied individuals.

Statement of Policy Regarding Accreditation

Where agencies exist for accreditation on specific aspects of services (e.g., Commission on Accreditation of Rehabilitation Facilities), affiliates should apply for accreditation of these areas of their program and so indicate such accreditation to the public which supports these efforts.

Where no accreditation exists, UCPA will develop guidelines and/or standards for services using other possible resources such as Child Welfare League (for Day Care Services).

Role of UCP State Associations

There should be a study done by National UCPA to clarify the role of state associations in relation to service program areas. Specific objectives and methods of achieving them should be outlined for state associations. One function of state organizations could be the utilization of Professional Service Program Committees to review, and possibly modify, standards according to specific problems within the state; to help interpret and "sell" the need for evaluations; and to encourage affiliates to apply for accreditation where available.

Role of Local Affiliates

Local affiliate boards often assume their characteristics from the initial affiliate projects and do not represent the horizon of needs of the cerebral palsied population in that area. Progress in the provision of services requires active participation of individuals representing virtually all phases of community life.

An affiliate should periodically conduct self-evaluation studies, review the pattern of services in its community or area, and plan at least five years ahead for possible program development or change. It may wish to take advantage of national survey team studies for future planning rather than for remediation of program problems that have become cumulative through neglect.

c. Timetable

This is a key current function of National UCPA and should continue at the same level as in the past. The development of more specific guidelines and instruments for self-study or for team evaluations should be started in 1969 but will probably take two or more years to complete. Establishment of minimum standards will be a long-range project and may only be begun by the end of the five year plan.

In order to start on the development of guidelines and instruments, it is proposed to constitute a Task Force which should have one meeting during fiscal 1968-69.

d. Financing

Fiscal 1968-69	-- Meeting of Task Force	- $1,500
	-- Professional Services (for Team Members)	- 8,000
		$9,500

Each subsequent year -- Same amounts, pending evaluation of this process by the Task Force.

2. Legislation in Service Programming

a. Rationale

UCP will never have sufficient funds to develop and carry on total service programs for all cerebral palsied persons needing assistance in the United States. Therefore, it must rely on federal and state public funds for the bulk of the service and educational efforts. However, these agencies move slowly and need to be stimulated and led by the voluntary health agency. Thus, not inconsiderably UCP effort should be placed in legislative programming, not as a lobbyist, but by carefully influencing legislation.

Objectives

-- To urge federal and state legislators to pass appropriate legislation or modify existing laws to provide additional and more effective services for individuals with cerebral palsy. This involves broadening of existing legislation to include persons with multiple handicaps, characteristic of cerebral palsied individuals.

-- To continue to disseminate information as to status of existing legislation and to interpret need for its passage to UCP and the community which it serves.

-- To develop model legislation and interpret to legislators the need for its introduction and passage.

-- To place appropriate citizen pressure on members of the Federal and state establishment to implement existing and future legislation of benefit to handicapped persons.

b. Methods

-- Broadening of the National Legislative Committee to include specialists in service program planning and execution.

-- Place a UCP representative in Washington in order to:

  -- Keep abreast of pending legislation and opinions of key legislators.

  -- Mobilize grass roots opinion and expedite their being brought to legislators.

  -- Ascertain where appropriate matching and initiatory funds may be obtained and assist affiliates in preparation of requests.

  -- Coordinate legislative activity with related agencies where the ultimate recipient is the person with multiple handicaps.

-- Encourage state and local Professional Services Program Committee to study existing legislation, interpret the need for its implementation and how persons with cerebral palsy can be included.

c. Timetable

1969 -- Washington representative (activated in 1968).
Interagency legislation committee meetings including staff of the Department of Health, Education and Welfare.
Broadening of Legislative Committee.
UCPA represented in planning, participation and followup of White House Conference on Children and Youth.

1970 -- National Conference on Legislative Needs -- Adjunct to White House Conference on Children and Youth (?)

d. Financing

Salary and travel of Washington Representative are part of Executive Department Budget. Legislative Committee expenses should be charged to that Department.

Fiscal 1969-70 -- UCPA participation in all aspects of White House Conference - $3,500

Fiscal 1970-71]
1971-72] -- Series of Regional Workshops for legislative and service programming;
1972-73] (Equal sharing with Legislative Department) - $2,500 per year

3. Professional Education

a. Rationale

The By-Laws recognize the concern of the United Cerebral Palsy Associations for "professional education in cerebral palsy." This concern includes responsibility for helping to increase the numbers of professional persons available. It is also important to foster the rapid integration of new knowledge and skills coming from research into the basic preparation of professional students; and to constantly update the competencies of graduates who care for the individual with cerebral palsy and his family. Responsibility for professional education is not restricted to one or two disciplines but includes all of the professions involved in programs of service and prevention.

b. Methods

-- It is recommended that an interdisciplinary Task Force be created as part of the Professional Services Program Committee structure to coordinate in one body all the elements of professional training and action previously scattered among a variety of advisory groups. This Task Force should have representation from the field of medicine, education, dentistry, psychology, nursing, therapy, recreation, social work, vocational rehabilitation, and family life education.

-- Duties assigned to this Task Force should include the following:
    -- Development of professional education priorities on the basis of all relevant professional disciplines in relationship to UCPA professional services needs.
    -- Consultation services to help develop media appropriate for use by professional school faculty members on the undergraduate and postgraduate levels; and for use in postgraduate seminars or other programs of community education carried out by professional associations.
    -- Evaluation of relative needs and advice to UCPA on the allocation of professional training monies.
    -- Serve as UCPA consultants for university or community programs of professional education.
    -- Advice and guidance for staff on matters of professional education.
-- A national staff member should be assigned to work directly with this Task Force and with that related to Staff Training.
-- Each Task Force member will be charged with the responsibility for determining the professional education needs within his profession and for recommending priorities for consideration by the Professional Education Task Force.

With reasonable consideration for other professional demands, each Task Force member will be expected to personally participate from time to time in selected programs of professional education of national importance; and to recommend others qualified to represent United Cerebral Palsy at professional association meetings, university or other programs of significance in professional education.

-- Task Force members will be expected to act as consultants in the preparation of professional education media related to priority program areas. These media will be prepared for use by university faculty members, professional associations developing postgraduate instructional courses, affiliates developing community workshops or seminars and related programs of professional education.

c. Timetable

Beginning in 1969 -- Constitution of Task Force and one meeting of same.

-- Preparation of materials.

-- Participation by Task Force members in Professional education programs.

Continuation of above activities in each subsequent year.

d. Financing

Money for professional education carries a high priority in a variety of governmental programs. There are governmental sources which fund well-constructed grant proposals for development of materials, sponsoring of workshops and seminars and as

seed money for postgraduate courses. However, there will be a need for UCPA funds for this function.

Fiscal 1968 - 1969	-- Meeting of Task Force	- $1,500
	-- Professional Services	- 3,000
	-- Fellowships	- 5,000
	-- Materials	- 2,000
		$11,500
Fiscal 1969 - 1970	-- Two Meetings of Task Force	- $ 3,000
	-- Professional Services	- 3,000
	-- Preparation of Materials	- 5,000
	-- Matching funds related to fellowships for student field training in areas of greatest unmet need (Program administration, recreation, social work, early childhood education, nursing, etc.)	- 10,000
		$21,000
Fiscal 1970-71, Fiscal 1971-72, Fiscal 1972-73	-- Continue as in 1969-70, but increase Fellowships to $15,000 as new avenues are developed to support the special professional education interests of UCPA, but total to remain at least at $26,000 level.	

4. Public Education Related to Service

a. Rationale

Internally, UCPA public education activities should utilize all recognized media to better inform the staffs, board and parent organizations concerning the need to provide total services. Externally, public education programs should provide more material aimed at educating the general public in a more realistic way concerning the all-encompassing aspects of the disabilities encountered by individuals with cerebral palsy and the impact of this on family life. The end goal should be aimed at public acceptance of the individual with cerebral palsy so that he may live in the community he chooses. Interpretation of research programs and of research findings must be made to the public in more commonly used nomenclature to promote better public understanding of cerebral palsy.

An intensified public education program is needed to dramatize and delineate the service aspects of the UCP program. It should include the scope of cerebral palsy from minimal dysfunction through severe physical disability and understanding and acceptance of the disabled person in the community.

The public thinks of "walking" as the goal of service programming. This has to be broadened in order to meet the wide variety of needs that must be satisfied in order to assure lives of purpose and dignity for handicapped children and adults. This implies being accepted in the community and sharing its regular and special opportunities as a participant, not as a separated beneficiary.

b. Methods

Basic responsibility for disseminating the content should rest with the Public Relations Department. However, the content should be established in cooperation with the Professional Services Program Committee and the Medical and Scientific Department.

c. Timetable

This effort should be started immediately and continued throughout the five year period.

d. Financing

Budget allocations for this function should be made to the Public Relations Department.

5. Demonstration Projects

a. Rationale

Many new approaches to services have been developed by one or more affiliates across the country (e.g., prenursery programs). In order to make these available to individuals with cerebral palsy in other communities, it is frequently necessary to obtain "seed money" to initiate and demonstrate the value of such services. In like manner, innovative ideas for programming (e.g., services to infants or for non-working adults and patterns for delivery of services in rural areas) need to be tested out in a variety of community settings. Most affiliates are not able to start new programs without some "seed money". Frequently, matching funds from other voluntary agencies, organizations and foundations, or from governmental sources can be obtained for new approaches to service if seed money is available.

Such provision of seed money for demonstration service programs is not a new concept to National UCPA for such funds have been provided in the past to develop successful services, (i.e. Home Service Program, UCP of Pennsylvania).

b. Methods

-- Seed money should be budgeted by National UCPA to help start programs in communities - both those that are new to that community and those which need demonstration. Such money should be used to match local affiliate monies or other resources they may find in their communities. The National UCPA budget should include a specific amount annually for this purpose. A project request process

should be established to include the steps necessary for approval. Seed money should be made available for specific projects for a period of three years, on a declining basis. This implies that the affiliates must plan in advance for financial support of the project on a continuing basis. Such projects will be carefully followed by National with consultation, advice and periodic evaluation as to the value of such seed money funding.

The role of state affiliates in this process is identified as follows:

-- The state might be able to grant seed money;

-- State could apply for projects in nonaffiliated areas;

-- The state association should assist affiliates in a consultative capacity. Such a relationship will help in allowing for the establishment of priorities within the state.

-- National should budget funds for nationwide service projects such as: development of evaluative instruments and patterns for use by local affiliates and by study teams; development of standards for affiliate service and special education programs; survey of transportation problems and patterns. Matching funds may be available from government sources or from private sources.

-- In certain instances the possibility of loans from National for these purposes should also be considered. These have been successful in showing up total affiliate programs to establish or solidify current services of an affiliate for proper identification by the public of its service program.

c. Timetable

Several affiliates can quickly develop action-oriented demonstration projects within the priority recommendations if seed money were made available within the next fiscal year. Probably others would be forthcoming in future years as National Task Forces develop suitable guidelines for such projects. It is estimated that five, at least, could be initiated during the first year and an additional ten in each of the subsequent four years of the plan.

d. Financing

Fiscal 1968-69	--	New Projects (possibly five at an average of $3,000 each)	- $15,000
Fiscal 1969-70	--	Continuation of ongoing projects at a reduced level	- $10,000
		New Projects	- 20,000
			$30,000
Fiscal 1970-71	--	Continuation of ongoing projects	- $25,000
		New Projects	- 20,000
			$45,000
Fiscal 1971-72	--	Continuation of ongoing projects	- $30,000
		New Projects	- 30,000
			$60,000
Fiscal 1972-73	--	Same as for previous year	- $60,000

Funding as outlined above would enable National UCPA to assist possibly 40 affiliates in the initiation of new service projects; and help support them on a declining basis for a period of three years. These national funds would be used to match money from federal, state and local government or other sources. The projects would be recommended for support by one of the Task Forces and approved by a standing committee of the Board of Directors -- namely, the Professional Services Program Committee.

6. Action Research

a. Rationale

It is generally accepted that more is known regarding primary prevention and prophylactic prevention of severe disability than is put into practice generally across the country. For example, many of the factors which place mothers in the high risk category are well known but little is done to follow-up consistently on such high risk mothers.

Since the emphasis of the UCP Research and Educational Foundation is now being placed on the stimulation and support of research related to suspected or known causative factors in brain dysfunction, the new program may permit some support of clinical research projects in concert with state or local affiliates such as provision of prenatal care services, etc. These could relate specifically to programs for maternal and infant care, identification of high risk mothers and prevention of secondary disabilities.

b. Methods

The usual procedures for application and granting of research requests would be applicable here.

c. Timetable

Depending upon recommendations of the Foundation's Task Forces it might be able to support two or three such projects during the first year and perhaps as many as five in subsequent years.

d. Financing

Determination of the appropriate amounts for this purpose would be made by the UCPA Research and Educational Foundation.

7. Cooperative Programming

a. Rationale

UCPA and its affiliates cannot possibly provide directly all the services needed by individuals with cerebral palsy and their families. Even if possible, this would not be desirable; since it would result in the complete isolation of all persons in this particular disability group. One of the major responsibilities of UCPA affiliates, therefore, is to see that maximum use is made of all possible resources in the community for individuals with cerebral palsy.

b. Methods

-- Cooperation with national fraternal groups is a responsibility of National UCPA. Special approaches should be made to the National Elks and the Grotto Foundation among others.

-- Cooperation with other national service agencies in:

-- Broad aspects of public education and public policy.

-- Mutual nationwide service problems:

-- Elimination of architectural barriers

-- Establishment of standards and accreditation of facilities

-- Legislation - innovations and revision

-- Patterns of service in areas with sparse population and scattered facilities

-- Residential care patterns

-- Care in state institutions

-- Protective services

-- Umbrella operations.

Special Committee

Recognition is taken of the fact that National is

structuring a special committee to study all aspects of "umbrella" operations in relation to services in local communities. It is recommended that the charge to this committee be a broad one to include both community problems from such services but especially the successful ones and why they have been so. Certain items are called to the attention of this committee:

-- UCP of Pennsylvania's policy statement regarding purchase of services versus grants.

-- That purchase of service by third parties is becoming increasingly available. Affiliates should establish their costs for units of service in order to take advantage of these resources.

-- Claims that "umbrella" operations will save money should be carefully examined. Efficiency should not take priority over human considerations.

-- Coordinated services need not necessarily involve merged services or even central housing. Decentralization of services can be quite effective in appropriate circumstances.

-- The considerations in Section XIII of the Affiliate Aggregate Report should be carefully considered by this committee.

Responsibility of Local Affiliates

-- The affiliate service efforts in the community should be well planned and carefully and effectively executed so that if it becomes part of an "umbrella" operation

the program will be able to be maintained and the affiliate can retain its identity.

-- The primary concern of the local affiliate is the net result of services to individuals provided in the most expeditious manner possible.

-- Leadership by the affiliate in planning and implementation will help insure that the coordinated program will best serve the needs of those with cerebral palsy.

Role of the State Association

-- To be aware of all phases of the service programs of UCP affiliates in the state and for potential strengthening and extension through UCP action and cooperative efforts with related organizations.

-- To keep locals informed regarding problems, their solutions and pitfalls.

-- To keep national informed and to request consultative service when indicated.

c. Timetable

-- Approaches should be made to other national groups in the immediate future to develop cooperative efforts.

-- The special committee on "umbrella" operations will probably complete its assignment prior to the 1969 Annual Conference.

-- Implementation of policies will be a continuing function of national, state and local affiliates.

d. Financing

There would seem to be no requirement for specific budget appropriations for this function.

III. FINANCING SUMMARY

The details of financing for the various priorities are spelled out in each section. It is recognized that specific appropriations must be made on an annual basis through the usual Budget and Finance Committee channels.

It is proposed that a new approach to long-range financing be adopted in order to make possible advance planning for implementation. This would be modeled upon procedures used in financing Federal Government programs. As each new agency or program is established by law, specific amounts of money are authorized, usually on a three to five year basis. Actual appropriations, however, are made on a year to year basis as the total budget is developed.

As an example of the way this might operate in relation to the IHF Plan, consider Section II, C. 5, pp. 58-61. The proposal for funding demonstration projects is:

Fiscal 1968-69	$15,000
Fiscal 1969-70	30,000
Fiscal 1970-71	45,000
Fiscal 1971-72	60,000
Fiscal 1972-73	60,000

It is suggested that the Board of Officers recommend expenditures at approximately these levels for the entire five year period. The National budget allocation is $15,000 for 1968-69. As the program develops, smaller or larger sums will be indicated for each ensuing year. However, funds will not be committed for the later years until budgets for those years are prepared and approved.

Such advance recommendations will permit more intelligent, long-range planning.

IV. POLICY STATEMENTS FOR ACTION BY THE BOARD OF OFFICERS AND THE EXECUTIVE COMMITTEE

A. Be it resolved that the Basic Principles of Services as set forth in the Introduction to the IHF Plan ("The Individual with Cerebral Palsy and His Family") are adopted by United Cerebral Palsy Associations, Inc.

B. Be it resolved that the Priorities for Action as set forth in the IHF Plan be ratified and referred by the President of UCPA to appropriate committees of the Board of Directors for implementation and recommended to the state and local affiliates for action.

C. Be it resolved that a policy of recommending tentative expenditures be projected and adopted in order to implement the IHF Plan, recognizing that appropriations will be dependent upon approval and modifications of the budget each year.

9/13/68